# Childhood Cancer in Massachusetts 1990 - 1999

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### INTRODUCTION

Cancer in children differs from cancer in adults. The leading cancers that occur in adults are carcinomas, such as breast, prostate, bronchus and lung, and colorectal (1). These cancers arise from the tissues that line the internal and external surfaces of the body. The leading cancers that occur in children are leukemia, lymphomas, and central nervous system cancers (2). In addition, some of the risk factors for childhood cancers may differ from risk factors for adult cancers. Genetic factors and prenatal exposures may increase the risk of developing childhood cancer, as well as environmental, parental occupational, and medical factors (3). Because of these differences, this report focuses on childhood cancer in Massachusetts. A specific coding scheme, the International Classification of Childhood Cancer (ICCC), has been devised to group childhood cancers. The ICCC groups cancers primarily by morphology (form or structure) rather than site as in adult cancer (4).

Childhood Cancer in Massachusetts is specifically devoted to providing information about childhood cancers that occur in children (0-14 years) and adolescents (15-19 years). First, the report details statewide patterns of childhood cancer between 1990 and 1999, including trends in the incidence of childhood cancer, the most common childhood cancers at various ages, and rates of childhood cancer by race/ethnicity. Next, the report provides more detailed information on childhood cancer incidence by ICCC grouping, including trends over time and comparisons by age groups. The report briefly covers statewide patterns of childhood cancer mortality between 1990 and 1998. Finally, the appendices of the report show coding classifications and detailed tables on childhood cancer incidence and mortality.

### **METHODS**

### **Data Sources**

### Cancer Incidence

Massachusetts cancer incidence data are collected by the Massachusetts Cancer Registry (MCR). The MCR is a population based cancer registry, established by state law in 1980, that collects reports of all newly diagnosed cancer cases from all Massachusetts acute care hospitals and one medical practice association that maintains a cancer registry. The MCR collects information on *in situ* and invasive cancers, except basal and squamous cell carcinomas of the skin, and benign tumors of the brain and associated tissues.

The activities of the MCR involve data collection efforts that necessitate extensive interaction with hospital tumor registrars. Intensive data evaluation is also required to ensure data quality. The fundamental requirements of any central cancer registry include: a) complete registration, b) prevention of duplication, c) collection of uniform data (i.e., standardization of items, definitions, rules, classification and nomenclature of primary site, histology, staging and procedures), d) quality control and e) efficient data processing.

MCR case ascertainment improved during the years covered by this report as additional case sources became available. For all diagnosis years, the MCR collects incident case information from diagnosing hospitals and hospitals providing initial treatment. For diagnosis year 1995 and onward, the MCR collects information from reporting hospitals on cases diagnosed and initially treated at other facilities, but receiving subsequent therapy or being diagnosed or treated for the cancer's progression or recurrence at the reporting facility. For diagnosis year 1996 and onward, the MCR collects information from reporting hospitals on cases diagnosed and treated in staff physician offices, when this information is available. However, not all hospitals report this type of case because reporting is optional for physician office only cases. Most cases of childhood cancer would not be diagnosed or treated solely in staff physician offices so this source of cases does not greatly affect childhood cancers. For diagnosis year 1997 and onward, the MCR conducts "death clearance" to identify cases of cancer reported on death certificates which had not been reported to the MCR. The MCR obtains additional information on these cases through follow-up activities with hospitals, nursing homes and physicians' offices. For some cases, however, the death certificate is the only source of information. From 1997 to 1999, there was just one child who was identified only through information from the death certificate.

Childhood cancer is rare and typically requires treatment by pediatric oncology specialists who are overwhelmingly connected with tertiary centers and teaching hospitals. When treatment or diagnostic tests are conducted in outpatient facilities, these facilities are usually attached to a hospital. Therefore, the MCR data collection system should be capturing the majority of childhood cancers statewide.

Since diagnosis year 1995, each year the North American Association of Central Cancer Registries (NAACCR) reviews cancer registry data for quality, completeness, and timeliness. For diagnosis year 1997-1999, the MCR's total case count was estimated by the NAACCR to be complete and the MCR was awarded a gold certificate by the NAACCR for quality, complete, and timely data.

The Massachusetts incidence data summarized in this report were drawn from data entered on MCR computer files before February 2002. The numbers may change slightly in future reports due to late reported cases or corrections based on subsequent details from the reporting facilities. Data in this report include <u>invasive</u> cancers diagnosed from 1990 to 1999 among Massachusetts residents less than 20 years old (children 0-14 years and adolescents 15-19 years). Case reports for 1990 were coded following the International Classification of Diseases for Oncology, First Edition (ICD-O-1) system and then converted to the International Classification of Diseases for Oncology, Second Edition (ICD-O-2) system. Case reports for 1991-1999 were coded following the ICD-O-2 system. All of the cases were grouped into ICCC categories. The ICCC system groups ICD-O-2 morphology (form or structure) and topography (site) codes into 12 major categories (4) (Appendix I). Although the ICCC includes some tumors of benign or uncertain behavior in its classification of central nervous system and intracranial and intraspinal neoplasms, those tumors are not included in this report. The Massachusetts data include invasive cancers only.

The national childhood cancer incidence data are from the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program. The SEER program includes

data from population-based cancer registries in 18 states and geographic areas, covering approximately 26% of the United States population. Unless otherwise noted, the SEER incidence data presented in this report are from 9 SEER areas during 1990 to 1999 among males and females 0-19 years old. Data from the 3 supplemental SEER registries and the 6 SEER registries that began collecting data after 1990 are not included in this report. The data are for malignant cancers only and have been categorized by the ICCC. The national incidence data were obtained from the SEER 1973-1999 public-use data (5) using the SEER\*Stat 4.2.6 software.

## **Cancer Mortality**

Massachusetts childhood cancer death data are from the Massachusetts Registry of Vital Records and Statistics, which has legal responsibility for collecting reports of deaths. Death reports from 1990 to 1998 were coded using the International Classification of Diseases, Ninth Revision (ICD-9). Data in this report include cancer deaths from 1990 to 1998 among Massachusetts residents less than 20 years of age (children 0-14 years and adolescents 15-19 years). Although more recent death data are available, they have been coded using the International Classification of Diseases, Tenth Revision (ICD-10). Only death data through 1998 are included in this report so that data collected with similar coding are combined or compared over time.

The national childhood cancer mortality data are based on data from the National Center for Health Statistics. Unless otherwise noted, the national mortality data presented in this report are for males and females 0-19 years old who died between 1990 and 1998. The national mortality data were obtained from the SEER 1973-1999 public-use data (5) using the SEER\*Stat 4.2.6 software.

### **Statistical Calculations**

Age-adjusted incidence and mortality rates presented in this report were calculated by the direct method to correct for differences in the age distributions of different populations. Age-adjusted rates were calculated by weighting the age-specific rates within five-year age groups during a given period by the age distribution of a standard population. The weighted age-specific rates were then added to produce the adjusted rate for all ages combined. The 2000 U.S. population distribution was used as the standard. The age-adjusted rates are presented as rates per 100,000 population. Rates can only be compared if they have been adjusted to the same standard. Age-adjusted cancer incidence and mortality rates presented in this report may differ from those in other reports which used a different standard such as the 1940 or 1970 U.S. population.

Age-specific rates are specific for a particular age range. The age-specific rates in this report were calculated by dividing the number of people in an age group who were diagnosed with cancer or died of cancer in a given time frame by the number of people in that same age group overall in a given time frame. The age-specific rates are presented as rates per 100,000.

For the computation of Massachusetts incidence and mortality rates in this report, the statewide population for individual years is based on population estimates released by the Massachusetts Institute for Social and Economic Research (MISER) in September, 2000. Rates are not calculated if the number of cases is less than 5 because they are unstable.

The estimated annual percent change (EAPC) is used to examine trends over time. In this report, the EAPC was calculated based on methods from the National Cancer Institute's SEER program (6). The EAPC was calculated by fitting a regression line  $\ln(r) = mx + b$ , where  $\ln(r)$  is the natural logarithm of the rates, x is the year, and m is the slope of the line, and then using the equation EAPC =  $100(e^m - 1)$ . A positive EAPC is indicative of an increasing trend, while a negative EAPC is indicative of a decreasing trend. The EAPC assumes that the change in rate is the same over the entire time period examined, which may or may not be true for the trends examined in this report. All of the EAPCs calculated in this report were tested against the hypothesis that they are equal to zero. A p value  $\leq 0.05$  was used to determine statistical significance.

The race/ethnicity categories presented in this report are mutually exclusive. Cases and deaths are only included in one race/ethnicity category. Individuals of Hispanic ethnicity are not included in a race group. The race/ethnicity categories are white, non-Hispanic; black, non-Hispanic; Asian/Pacific Islander, non-Hispanic; and Hispanic. American Indians/Aleutians/ Eskimos are not included as a race/ethnicity category because of the small number of cases of childhood cancer among this group.

### **Data Limitations**

When interpreting the cancer data, it is important to consider certain limitations. These limitations include: under-reporting in areas close to neighboring states, potentially misleading trends, small numbers of cases, and misclassification and/or under-reporting of race/ethnicity data. Although the MCR has reciprocal reporting agreements with fifteen states, including all New England states, there may still be loss of cases in Massachusetts residents who were diagnosed in neighboring states and not reported to the MCR. Apparent increases or decreases in cancer incidence over time may reflect changes in diagnostic methods or case reporting rather than true changes in cancer occurrence. Many of the calculations in this report involved small numbers of cases. As a result, the data should be interpreted with caution. Finally, data on race/ethnicity are based on information existing in the medical record for cancer cases and information on the death certificate for cancer deaths. Errors in these source documents may lead to incorrect classification of race/ethnicity. Also, some race/ethnicity categories may be under-reported since race/ethnicity is not available for all cases. Counts and rates presented may under-represent the true incidence in some race/ethnic populations.

### STATEWIDE PATTERNS OF CHILDHOOD CANCER INCIDENCE

### Overview

During 1990-1999, 2,688 cases of invasive cancer were diagnosed in Massachusetts among children and adolescents less than 20 years old, approximately 270 cases per year. About 53% of these childhood cancers occurred in males and 47% in females. The average annual age-adjusted incidence rate of childhood cancer in Massachusetts during 1990-1999 was 16.7 cases per 100,000. This combined rate is slightly higher than the national incidence rate of childhood cancer in the SEER areas during 1990-1999 of 16.1 per 100,000. In Massachusetts, the age-adjusted incidence rate of childhood cancer was higher for males than females, 17.4 cases per 100,000 males and 16.1 cases per 100,000 females.

### **Trends**

From 1990 to 1999, the age-adjusted incidence rate of childhood cancer did not increase or decrease greatly for either Massachusetts males or females (Figure 1). The age-adjusted incidence rate of cancer for Massachusetts males was 16.0 cases per 100,000 males in 1990 and 17.0 cases per 100,000 males in 1999. The estimated annual percent change (EAPC) during this time period showed a decreasing trend of -0.7% per year for childhood cancer among males. For Massachusetts females, the age-adjusted incidence rate of cancer was 14.7 cases per 100,000 females in 1990 and 15.9 cases per 100,000 females in 1999, and the EAPC showed an increasing trend of 1.6% per year from 1990 to 1999. However, neither the EAPC for males nor for females was statistically significant. Data from the SEER program indicate that nationally, from 1975 to 1995, there were no large increases or decreases in the incidence of the major cancers among children less than 15 years old (7).

Figure 1: Trends in cancer incidence among children and adolescents less than 20 years old, Massachusetts, 1990-1999

25.0

15.0

10.0

1990 1991 1992 1993 1994 1995 1996 1997 1998 1999

Year

\* Age-adjusted to the 2000 U.S. Standard Population.

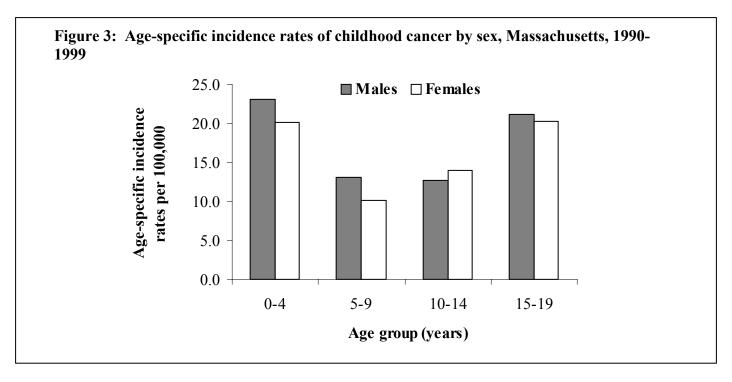
## **Most Common Types**

According to the ICCC diagnostic groupings, the three most common cancers among all Massachusetts children and adolescents less than 20 years old from 1990 to 1999 were leukemia, central nervous system cancers, and lymphomas (Appendix III). These three cancers accounted for 60% of childhood cancer in males and 53% of childhood cancer in females. No other grouping accounted for more than 10% of childhood cancer in either sex, except for carcinomas and other malignant epithelial neoplasms among females (Figure 2).

Figure 2: Distribution of cancer incidence among children and adolescents less than 20 years old, Massachusetts, 1990-1999 **MALES** Other & Hepatic Retinoblastoma Unspecified 2.0% 1.6% 0.1% Renal Carcinomas & 4.4% Other Epithelial Leukemia 5.2% 23.8% Bone 5.4% Germ-cell 6.3% Sympathetic Nervous Lymphoma System 18.6% 6.5% Central Soft Tissue Nervous Sarcoma 8.5% System 17.4% **FEMALES** Retinoblastoma Other & Hepatic Unspecified 1.6% 1.3% 1.0% Renal 4.6% Leukemia Soft Tissue Bone 22.4% Sarcoma 4.8% 6.1% Sympathetic Nervous System 6.4% Central Nervous Germ-cell System 6.7% 16.7% Carcinomas & Lymphoma Other Epithelial 13.9% 14.5%

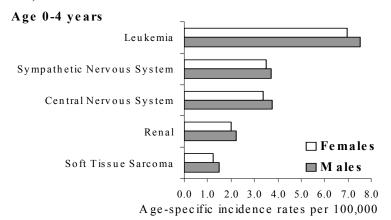
## **Age Patterns**

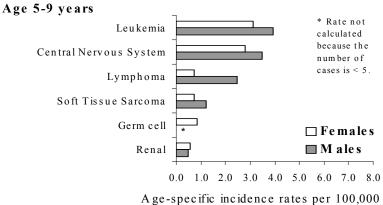
The age-specific incidence rate of childhood cancer was highest among Massachusetts males and females 0-4 years old and 15-19 years old from 1990 to 1999 (Figure 3).

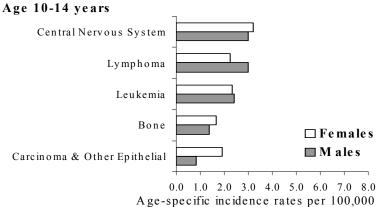


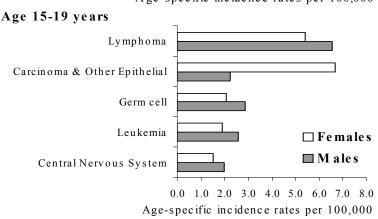
In Massachusetts from 1990 to 1999, the most commonly occurring childhood cancer groupings varied by age group and sex (Figure 4). For Massachusetts males and females combined, leukemia was the most commonly diagnosed cancer grouping among 0-4 year olds and 5-9 year olds during 1990 to 1999. Central nervous system cancers was the most common cancer diagnostic group for all those 10-14 years old, and lymphomas was the most common cancer diagnostic group for all those 15-19 years old (Appendix IV).

Figure 4: Age-specific incidence rates of leading childhood cancers by age group and sex, Massachusetts, 1990-1999



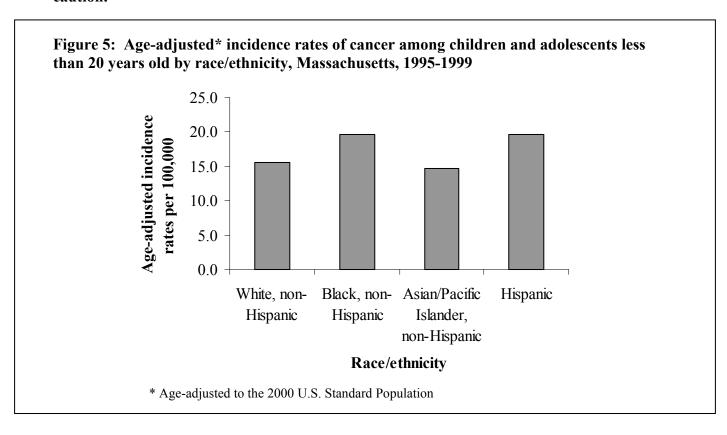






## **Race/Ethnicity Patterns**

Among Massachusetts children and adolescents less than 20 years old from 1995 to 1999, black, non-Hispanics and Hispanics had higher overall age-adjusted incidence rates of cancer than white, non-Hispanics and Asian/Pacific Islander, non-Hispanics (Figure 5). During this time period, the age-adjusted incidence rate was 19.6 cases per 100,000 for black, non-Hispanic children and adolescents and 19.7 cases per 100,000 for Hispanic children and adolescents. The Massachusetts Cancer Registry did not collect reliable race/ethnicity data before 1995. It should be noted that many of the calculations in this report involve small numbers of cases. The differences in the rates may be due to chance, and the data should be interpreted with caution.



### SITE-SPECIFIC PATTERNS OF CHILDHOOD CANCER INCIDENCE

### **LEUKEMIA**

### **Overview**

Leukemia is a group of cancers that develop in the blood-forming tissues. Leukemia was the most commonly occurring cancer among both Massachusetts males and females less than 20 years old during 1990-1999, accounting for over 20% of childhood cancers in each sex. Between 1990 and 1999, 339 cases of childhood leukemia were diagnosed among males and 282 cases were diagnosed among females in the state. During that time period, the age-adjusted incidence rate of leukemia among Massachusetts children and adolescents less than 20 years old was slightly higher for males than females, with 4.1 per 100,000 for males and 3.5 per 100,000 for females. The incidence rate of childhood leukemia in Massachusetts was similar to the national incidence rate based on SEER data for males, females, and total (Table 1).

Table 1: Age-adjusted incidence rates\* of leukemia among children and adolescents less than 20 years old, Massachusetts and SEER areas, 1990-1999

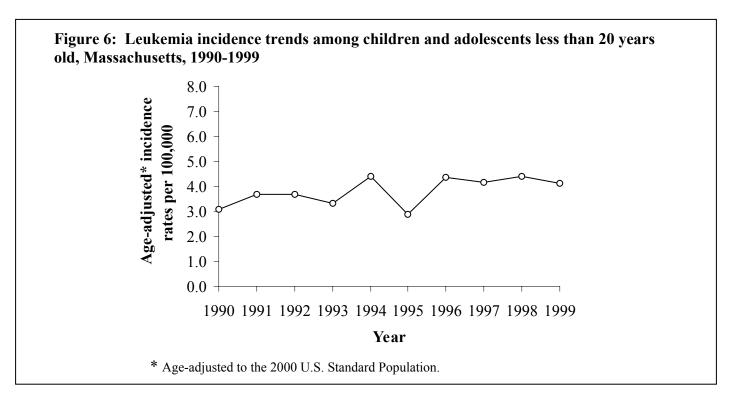
|         | Massachusetts | SEER areas |
|---------|---------------|------------|
| Males   | 4.1           | 4.3        |
| Females | 3.5           | 3.5        |
| Total   | 3.8           | 3.9        |

<sup>\*</sup>per 100,000. Age-adjusted to the 2000 U.S. Standard Population

### **Trends**

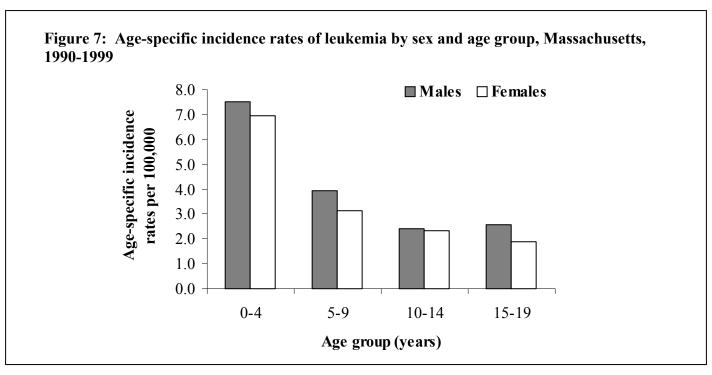
Between 1990 and 1999, the incidence rate of leukemia among Massachusetts children and adolescents less than 20 years old increased slightly, from 3.1 cases per 100,000 in 1990 to 4.1 cases per 100,000 in 1999 (Figure 6). The estimated annual percent change (EAPC) for leukemia from 1990 to 1999 was 3.0% per year, reflecting an increasing, though not statistically significant, trend in childhood leukemia in the state during that time period.

Nationally, the incidence of leukemia among children under age 15 years increased abruptly from 1983 to 1984 by 22%. However, there has been a slight decrease in the national incidence rate of leukemia among children under age 15 years since 1989 (7).



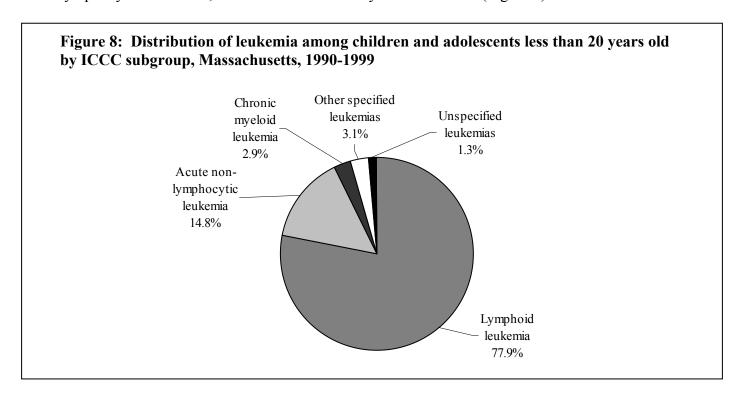
# **Age Patterns**

Between 1990 and 1999, the incidence rate of childhood leukemia was highest among Massachusetts males and females 0-4 years old, with 7.5 cases per 100,000 males and 7.0 cases per 100,000 females (Figure 7). The incidence rate of leukemia was lower among the other age groups.



# **Most Common Types**

Of all the leukemia occurring between 1990 and 1999 among Massachusetts children and adolescents less than 20 years old, 78% were lymphoid leukemias, 15% were acute nonlymphocytic leukemias, and 3% were chronic myeloid leukemias (Figure 8).



### LYMPHOMAS AND RETICULOENDOTHELIAL NEOPLASMS

### Overview

Lymphomas are cancers that develop from the lymphatic or reticuloendothelial (lymphocyte supporting tissue) system, the system of the body that helps fight infection and disease. Lymphomas were the second most commonly occurring childhood cancers among Massachusetts males and the fourth most commonly occurring childhood cancers among Massachusetts females between 1990 and 1999. During this time period, lymphomas and other reticuloendothelial neoplasms accounted for about 19% of all cancers occurring among Massachusetts males less than 20 years old and 14% of all cancers occurring among Massachusetts females less than 20 years old. Between 1990 and 1999, 266 cases of childhood lymphoma were diagnosed among males and 175 cases were diagnosed among females in the state. The age-adjusted incidence rate of lymphoma among children and adolescents less than 20 years old was higher for males than for females, 3.3 per 100,000 for males and 2.3 per 100,000 for females. The incidence rate of childhood lymphomas in Massachusetts was slightly higher than the national incidence rate based on SEER data for males, females, and total (Table 2).

Table 2: Age-adjusted incidence rates\* of lymphomas among children and adolescents less than 20 years old, Massachusetts and SEER areas, 1990-1999

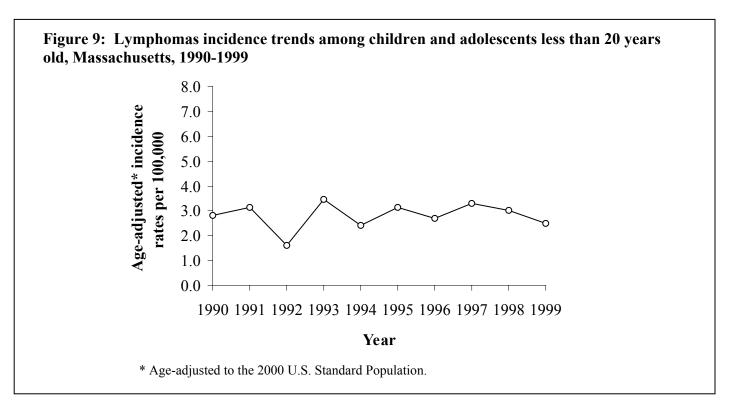
|         | Massachusetts | SEER areas |
|---------|---------------|------------|
| Males   | 3.3           | 2.7        |
| Females | 2.3           | 2.0        |
| Total   | 2.8           | 2.3        |

<sup>\*</sup>per 100,000. Age-adjusted to the 2000 U.S. Standard Population

### **Trends**

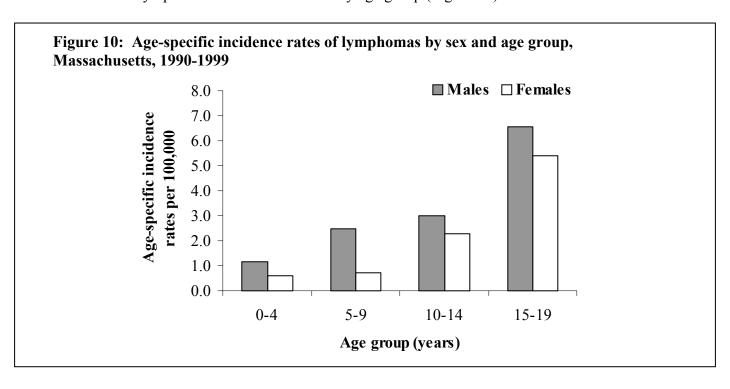
Between 1990 and 1999, the incidence rate of lymphomas among Massachusetts children and adolescents less than 20 years old fluctuated between 1.6 and 3.5 cases per 100,000 (Figure 9). The incidence rate of childhood lymphomas among Massachusetts children and adolescents was 2.8 cases per 100,000 in 1990 and 2.5 cases per 100,000 in 1999. The estimated annual percent change (EAPC) for childhood lymphomas in Massachusetts from 1990 to 1999 was 1.0% per year, a slight increasing trend, though the trend was not statistically significant.

Nationally, the incidence of lymphoma among children under age 15 years decreased from 1975 to 1995. This decrease was statistically significant and was primarily due to a decline in the incidence of Hodgkin's disease (7).



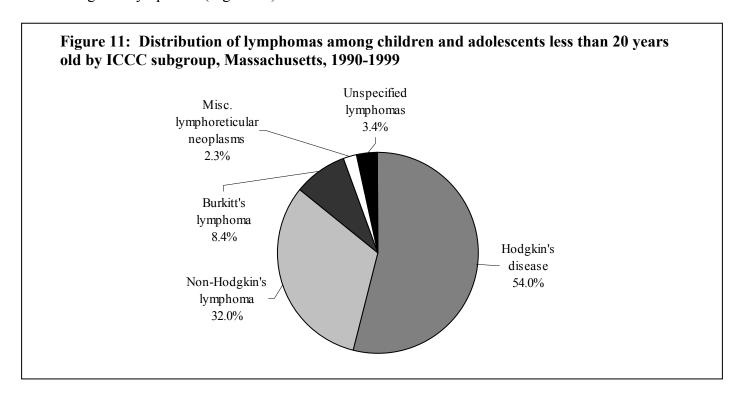
# **Age Patterns**

The incidence rate of childhood lymphomas was highest among Massachusetts adolescents 15-19 years old, with 6.6 cases per 100,000 males and 5.4 cases per 100,000 females between 1990 and 1999. During this time period, the incidence rate of childhood lymphoma increased with increasing age group. Between 1990 and 1999, Massachusetts males had a higher incidence rate of childhood lymphomas than females in every age group (Figure 10).



# **Most Common Types**

Of all the lymphomas occurring between 1990 and 1999 among Massachusetts children and adolescents less than 20 years old, over 50% were Hodgkin's disease and 32% were non-Hodgkin's lymphoma (Figure 11).



# CENTRAL NERVOUS SYSTEM AND MISCELLANEOUS INTRACRANIAL AND INTRASPINAL NEOPLASMS

### Overview

Central nervous system and miscellaneous intracranial and intraspinal neoplasms (CNS tumors) include tumors that arise from the brain, spinal cord, and other sites within the skull and spinal cord. These tumors were the third most commonly occurring childhood cancers among Massachusetts males and the second most commonly occurring childhood cancers among Massachusetts females between 1990 and 1999. CNS tumors accounted for 17% of childhood cancer in both Massachusetts males and females. Between 1990-1999, 249 childhood CNS tumors were diagnosed among males and 211 cases were diagnosed among females in the state. During this time period, the age-adjusted incidence rate of CNS tumors among Massachusetts children and adolescents less than 20 years old was slightly higher for males than females, 3.1 per 100,000 for males and 2.7 per 100,000 for females. The incidence rate of childhood CNS tumors in Massachusetts was similar to the national incidence rate based on SEER data for males, females, and total (Table 3).

Table 3: Age-adjusted incidence rates\* of CNS tumors among children and adolescents less than 20 years old, Massachusetts and SEER areas, 1990-1999

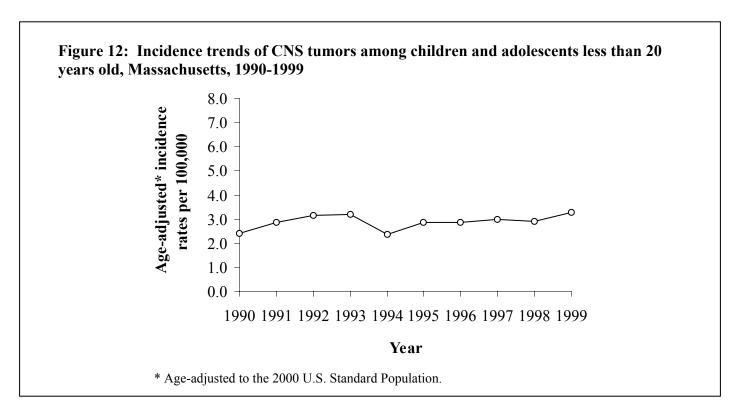
|         | Massachusetts | SEER areas |
|---------|---------------|------------|
| Males   | 3.1           | 3.2        |
| Females | 2.7           | 2.6        |
| Total   | 2.9           | 2.9        |

<sup>\*</sup>per 100,000. Age-adjusted to the 2000 U.S. Standard Population

### **Trends**

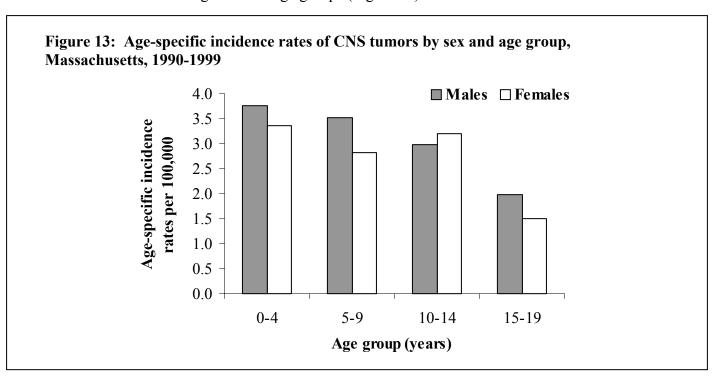
Between 1990 and 1999, the incidence rate of CNS tumors among Massachusetts children and adolescents less than 20 years old fluctuated between a low of 2.4 cases per 100,000 in 1990 and 1994 and a high of 3.3 cases per 100,000 in 1999 (Figure 12). The estimated annual percent change (EAPC) for CNS tumors from 1990 to 1999 was 1.5% per year, reflecting a slight increasing, though not statistically significant, trend in childhood CNS tumors in the state during that time period.

Nationally, the incidence of brain and other CNS cancers among children under age 15 years increased from 1983 to 1986 by 55%, but has remained stable since that time through 1995. It has been hypothesized that the increases in the mid 1980s may have been due to better diagnostic technology, such as magnetic resonance imaging, new surgical procedures, and classification changes (7).



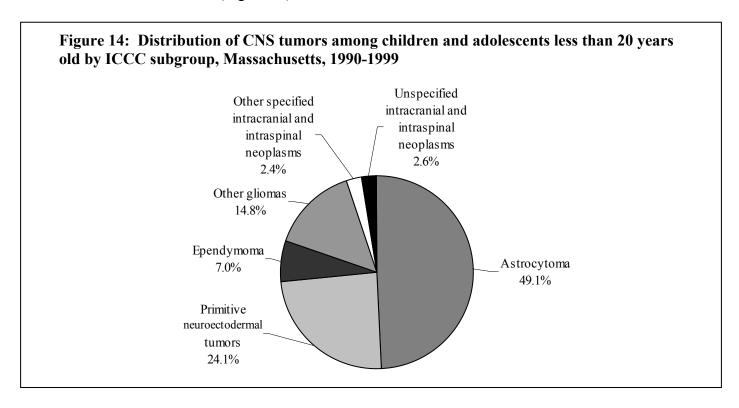
# **Age Patterns**

Among Massachusetts children and adolescents less than 20 years old, the incidence rate of CNS tumors from 1990 to 1999 was lowest among males and females 15-19 years old, at 2.0 cases per 100,000 males and 1.5 cases per 100,000 females. The incidence rates of childhood CNS tumors were more similar among the other age groups (Figure 13).



# **Most Common Types**

Of all the CNS tumors occurring between 1990 and 1999 among Massachusetts children and adolescents less than 20 years old, 49% were astrocytomas and 24% were primitive neuroectodermal tumors (Figure 14).



### SYMPATHETIC NERVOUS SYSTEM TUMORS

### Overview

The sympathetic nervous system (SNS) is part of the autonomic nervous system, which regulates involuntary activities of the heart muscle, smooth muscle, and glands. Between 1990 and 1999, tumors of the SNS accounted for about 7% of all cancers occurring among Massachusetts males and females less than 20 years old. During this time period, 174 SNS tumors were diagnosed among children and adolescents in the state (93 in males and 81 in females). The age-adjusted incidence rate of SNS tumors among Massachusetts children and adolescents less than 20 years old was 1.1 per 100,000 for males and 1.0 per 100,000 for females from 1990 to 1999. The incidence rate of childhood SNS tumors in Massachusetts was similar to the national incidence rate based on SEER data for males, females, and total (Table 4).

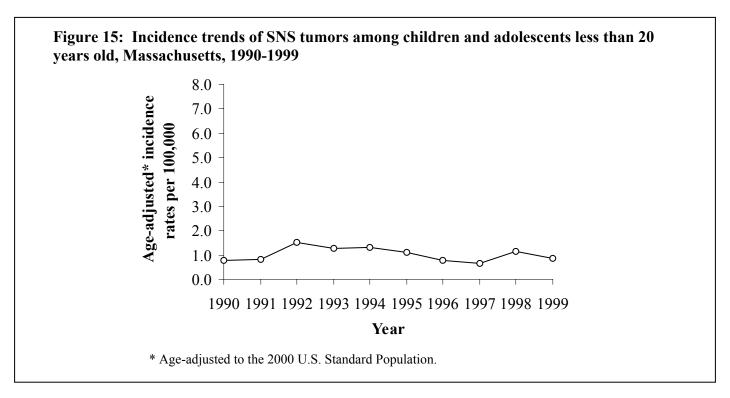
Table 4: Age-adjusted incidence rates\* of SNS tumors among children and adolescents less than 20 years old, Massachusetts and SEER areas, 1990-1999

|         | Massachusetts | SEER areas |
|---------|---------------|------------|
| Males   | 1.1           | 0.9        |
| Females | 1.0           | 0.8        |
| Total   | 1.0           | 0.8        |

<sup>\*</sup>per 100,000. Age-adjusted to the 2000 U.S. Standard Population

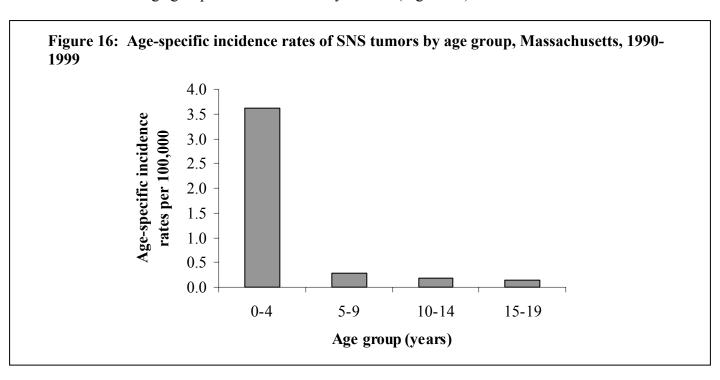
### **Trends**

Between 1990 and 1999, the age-adjusted incidence rate of SNS tumors among Massachusetts children and adolescents less than 20 years old showed minor year to year fluctuations, but the rate was 0.8 cases per 100,000 in both 1990 and 1999 (Figure 15). The estimated annual percent change (EAPC) for childhood SNS tumors in Massachusetts during this time period was -1.6% per year, a slight decreasing trend. This trend was not statistically significant.



# **Age Patterns**

The incidence rate of childhood SNS tumors from 1990 to 1999 was highest among Massachusetts children 0-4 years old, with 3.6 cases per 100,000. About 86% of newly diagnosed cases of childhood SNS tumors occurred among children in this age group. From 1990 to 1999, the incidence rate of SNS tumors was less than 0.4 cases per 100,000 in all of the Massachusetts age groups between 5 and 19 years old (Figure 16).



# **Most Common Types**

Of all the SNS tumors occurring between 1990 and 1999 among Massachusetts children and adolescents less than 20 years old, 98% were neuroblastomas or ganglioneuroblastomas and the remainder were other SNS tumors.

### RETINOBLASTOMA

### Overview

Retinoblastoma is a cancer of the eye that occurs among very young children (2). About 40% of cases of retinoblastoma are due to inherited mutations (changes) in a retinoblastoma related gene. The remaining 60% of cases of retinoblastoma result from sporadic (random) mutations in a gene (8).

Retinoblastoma was one of the least commonly occurring cancers among Massachusetts children and adolescents less than 20 years old between 1990 and 1999, accounting for only 1.8% of all childhood cancers in the state. During this time period, 49 cases of retinoblastoma were diagnosed among children and adolescents in the state. The age-adjusted incidence rate of retinoblastoma among Massachusetts children and adolescents less than 20 years old was 0.3 per 100,000 for males and 0.2 per 100,000 for females from 1990-1999. The incidence rate of childhood retinoblastoma in Massachusetts was similar to the national incidence rate based on SEER data for males, females, and total (Table 5).

Table 5: Age-adjusted incidence rates\* of retinoblastoma among children and adolescents less than 20 years old, Massachusetts and SEER areas, 1990-1999

|         | Massachusetts | SEER areas |
|---------|---------------|------------|
| Males   | 0.3           | 0.3        |
| Females | 0.2           | 0.4        |
| Total   | 0.3           | 0.3        |

<sup>\*</sup>per 100,000. Age-adjusted to the 2000 U.S. Standard Population

## **Age Patterns**

In Massachusetts, over 95% of newly diagnosed cases of childhood retinoblastoma from 1990 to 1999 occurred among children 0-4 years old.

Note that no graphs are presented for childhood retinoblastoma because of the small number of cases.

### **RENAL TUMORS**

### Overview

Between 1990 and 1999, renal (kidney) tumors accounted for just under 5% of all cancers occurring among Massachusetts males and females less than 20 years old. During this time period, 121 cases of renal tumor were diagnosed among children and adolescents in the state. Between 1990-1999, the age-adjusted incidence rate of childhood renal tumors was the same for Massachusetts females and males, 0.7 cases per 100,000. The incidence rate of childhood renal tumors in Massachusetts was the same as the national incidence rate based on SEER data for males, females, and total (Table 6).

Table 6: Age-adjusted incidence rates\* of renal tumors among children and adolescents less than 20 years old, Massachusetts and SEER areas, 1990-1999

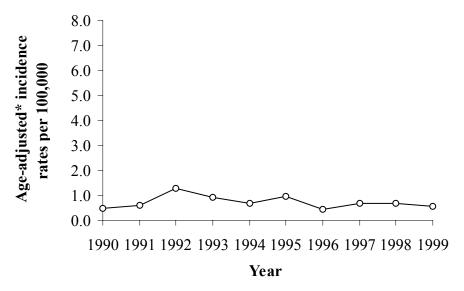
|         | Massachusetts | SEER areas |
|---------|---------------|------------|
| Males   | 0.7           | 0.7        |
| Females | 0.7           | 0.7        |
| Total   | 0.7           | 0.7        |

<sup>\*</sup>per 100,000. Age-adjusted to the 2000 U.S. Standard Population

### **Trends**

Between 1990 and 1999, the incidence rate of renal tumors among Massachusetts children and adolescents less than 20 years old fluctuated between 0.4 and 1.3 cases per 100,000. The incidence rate of childhood renal tumors was 0.5 cases per 100,000 in both 1990 and 1999 (Figure 17). The estimated annual percent change (EAPC) for childhood renal tumors in Massachusetts from 1990 to 1999 was -2.2% per year, a slight decreasing trend. This trend was not statistically significant.

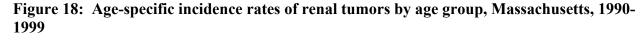
Figure 17: Incidence trends of renal tumors among children and adolescents less than 20 years old, Massachusetts, 1990-1999

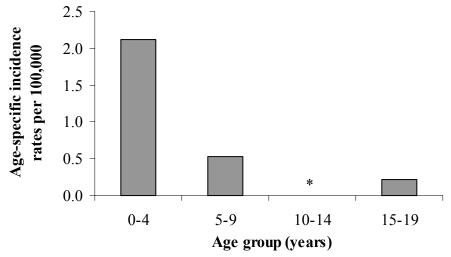


\* Age-adjusted to the 2000 U.S. Standard Population.

# **Age Patterns**

Among Massachusetts children and adolescents less than 20 years old, children 0-4 years old had the highest incidence rate of renal tumors from 1990 to 1999, with 2.1 cases per 100,000 (Figure 18).





\* Rate not calculated because the number of cases is < 5.

# **Most Common Types**

Of all the renal tumors occurring between 1990 and 1999 among Massachusetts children and adolescents, 91% were Wilms' tumor, rhabdoid and clear cell sarcoma, 8% were renal carcinoma, and the remainder were unspecified malignant renal tumors. Wilms' tumors, rhabdoid and clear cell sarcomas occurred most commonly among children less than 5 years old, with 79% of these cases occurring among these children.

Genetic factors have been linked to Wilms' tumor, and children with Wilms' tumor may have other congenital defects. There are several syndromes that include Wilms' tumor, including the Beckwith-Wiedemann syndrome, the Denys-Drash syndrome, and the WAGR syndrome (8).

### **HEPATIC TUMORS**

### Overview

Hepatic (liver) tumors were the least commonly occurring cancers among Massachusetts children and adolescents less than 20 years old between 1990 and 1999. They accounted for only 1.5% of all childhood cancers in the state. During this time period, 40 cases of hepatic tumors were diagnosed among children and adolescents in the state. The age-adjusted incidence rate of hepatic tumors among Massachusetts children and adolescents less than 20 years old was similar for males and females, 0.3 per 100,000 for males and 0.2 per 100,000 for females from 1990-1999. The incidence rate of childhood hepatic tumors in Massachusetts was similar to the national incidence rate based on SEER data for males, females, and total (Table 7).

Table 7: Age-adjusted incidence rates\* of hepatic tumors among children and adolescents less than 20 years old, Massachusetts and SEER areas, 1990-1999

|         | Massachusetts | SEER areas |
|---------|---------------|------------|
| Males   | 0.3           | 0.2        |
| Females | 0.2           | 0.2        |
| Total   | 0.2           | 0.2        |

<sup>\*</sup>per 100,000. Age-adjusted to the 2000 U.S. Standard Population

### **Age Patterns**

Among Massachusetts children and adolescents less than 20 years old, 65% of newly diagnosed cases of hepatic tumors from 1990 to 1999 occurred among children 0-4 years old.

## **Most Common Types**

Of all the hepatic tumors occurring during that time period among Massachusetts children and adolescents, 63% were hepatoblastomas, 35% were hepatic carcinomas, and the remainder were unspecified malignant hepatic tumors.

Note that no graphs are presented for childhood hepatic tumors because of the small number of cases.

### MALIGNANT BONE TUMORS

### Overview

Between 1990 and 1999, malignant bone tumors accounted for about 5% of all cancers occurring among Massachusetts children and adolescents less than 20 years old. During this time period, 137 malignant bone tumors were diagnosed among children and adolescents in the state. The age-adjusted incidence rate of malignant bone tumors among Massachusetts children and adolescents less than 20 years old was similar for males and females, 1.0 per 100,000 for males and 0.8 per 100,000 for females, from 1990-1999. The incidence rate of childhood malignant bone tumors in Massachusetts was similar to the national incidence rate based on SEER data for males, females, and total (Table 8).

Table 8: Age-adjusted incidence rates\* of malignant bone tumors among children and adolescents less than 20 years old, Massachusetts and SEER areas, 1990-1999

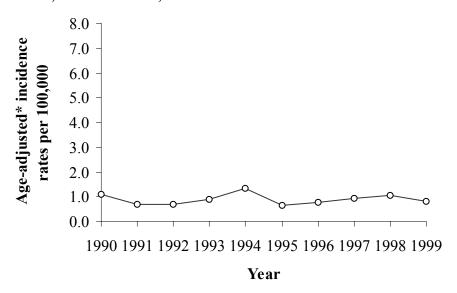
|         | Massachusetts | SEER areas |
|---------|---------------|------------|
| Males   | 1.0           | 1.1        |
| Females | 0.8           | 0.7        |
| Total   | 0.9           | 0.9        |

<sup>\*</sup>per 100,000. Age-adjusted to the 2000 U.S. Standard Population

### **Trends**

Between 1990 and 1999, the incidence rate of malignant bone tumors among Massachusetts children and adolescents less than 20 years old fluctuated between 0.6 and 1.3 cases per 100,000 and hovered around 1 case per 100,000 each year (Figure 19). The estimated annual percent change (EAPC) for childhood bone tumors was fairly stable, with a 0.5% increase per year. The EAPC was not statistically significant.

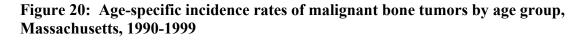
Figure 19: Incidence trends of malignant bone tumors among children and adolescents less than 20 years old, Massachusetts, 1990-1999

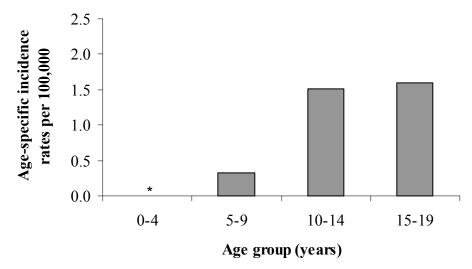


\* Age-adjusted to the 2000 U.S. Standard Population.

### **Age Patterns**

Between 1990 and 1999 in Massachusetts, the incidence rate of malignant bone tumors was higher in children 10-14 years old and adolescents 15-19 years old than in children 0-4 and 5-9 years old. During this time period, 10-14 year olds in Massachusetts had an age-specific incidence rate of malignant bone tumors of 1.5 cases per 100,000 and 15-19 year olds had an age-specific incidence rate of 1.6 cases per 100,000 (Figure 20).

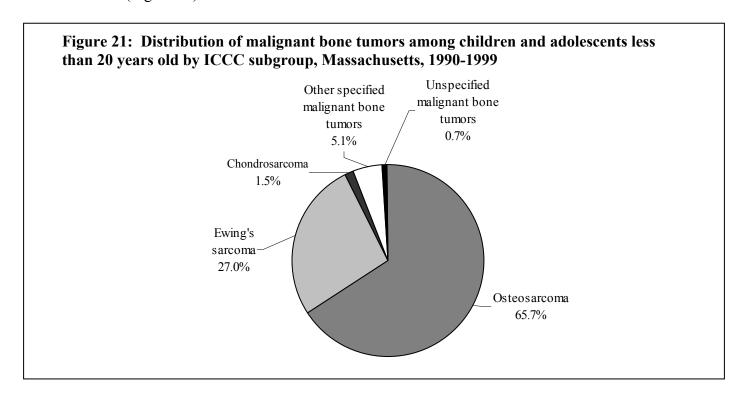




\* Rate not calculated because the number of cases is < 5.

## **Most Common Types**

Of all the malignant bone tumors occurring between 1990 and 1999 among Massachusetts children and adolescents less than 20 years old, 66% were osteosarcomas and 27% were Ewing's sarcomas (Figure 21).



#### **SOFT-TISSUE SARCOMAS**

#### Overview

Soft-tissue sarcomas are cancers that develop in the supporting tissues, such as muscle, fat, and blood vessels. Between 1990 and 1999, soft-tissue sarcomas accounted for about 7% of childhood cancer in Massachusetts, 9% for males and 6% for females. During this time period, 122 childhood soft-tissue sarcomas were diagnosed among males and 77 cases were diagnosed among females in the state. The age-adjusted incidence rate of soft-tissue sarcomas among Massachusetts children and adolescents less than 20 years old was slightly higher for males than females, 1.5 per 100,000 for males and 1.0 per 100,000 for females from 1990-1999. The incidence rate of childhood soft-tissue sarcomas in Massachusetts was slightly higher than the national incidence rate based on SEER data for males, but was similar to the national rate for females and total (Table 9).

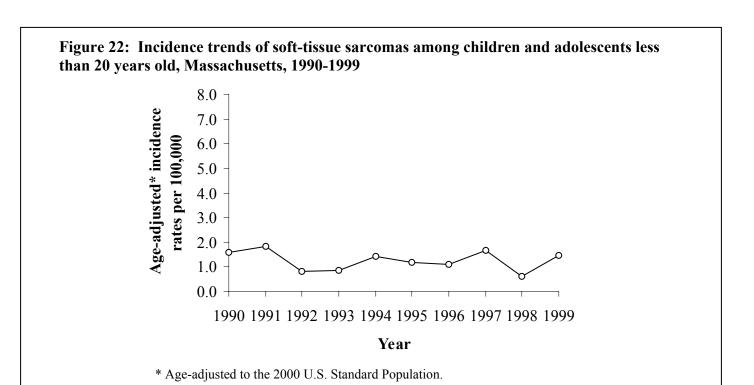
Table 9: Age-adjusted incidence rates\* of soft-tissue sarcomas among children and adolescents less than 20 years old, Massachusetts and SEER areas, 1990-1999

|         | Massachusetts | SEER areas |
|---------|---------------|------------|
| Males   | 1.5           | 1.2        |
| Females | 1.0           | 1.1        |
| Total   | 1.2           | 1.1        |

<sup>\*</sup>per 100,000. Age-adjusted to the 2000 U.S. Standard Population

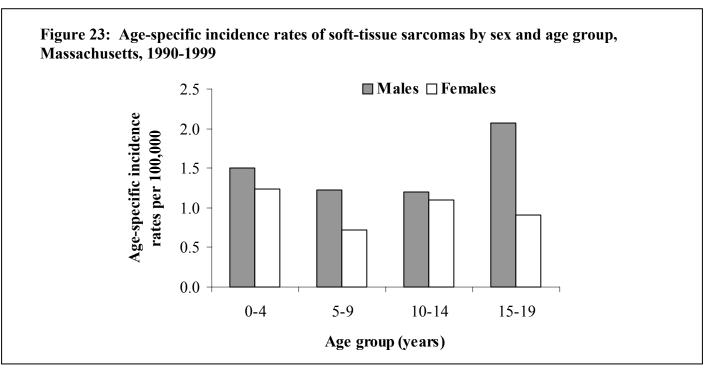
#### **Trends**

Between 1990 and 1999, the incidence rate of soft-tissue sarcomas among Massachusetts children and adolescents less than 20 years old fluctuated between 0.6 and 1.8 cases per 100,000 (Figure 22). The incidence rate of childhood soft-tissue sarcomas was 1.6 cases per 100,000 in 1990 and 1.5 cases per 100,000 in 1999. The estimated annual percent change (EAPC) for childhood soft-tissue sarcomas in Massachusetts from 1990 to 1999 was –2.4% per year, a slight decreasing, though not statistically significant, trend.



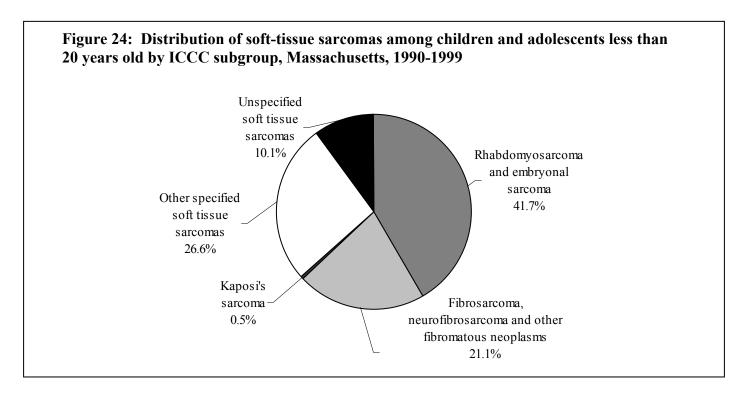
#### **Age Patterns**

The incidence rate of childhood soft-tissue sarcomas from 1990 to 1999 was highest among Massachusetts males 15-19 years old, with 2.1 cases per 100,000. For Massachusetts females, the incidence rate of childhood soft-tissue sarcomas was highest for those 0-4 and 10-14 years old during that time period, with 1.2 and 1.1 cases per 100,000 respectively. Between 1990 and 1999, Massachusetts males had a higher incidence rate of childhood soft-tissue sarcoma than females in every age group (Figure 23).



## **Most Common Types**

Of all the soft-tissue sarcomas occurring between 1990 and 1999 among Massachusetts children and adolescents less than 20 years old, approximately 42% were rhabdomyosarcomas and embryonal sarcomas and 21% were fibrosarcomas, neurofibrosarcomas and other fibromatous neoplasms (Figure 24).



#### GERM CELL, TROPHOBLASTIC AND OTHER GONADAL NEOPLASMS

#### Overview

Germ cell (egg or sperm), trophoblastic (cells outside an early embryo) and other gonadal (ovarian or testicular) neoplasms arise from reproductive cells. Between 1990 and 1999, germ cell, trophoblastic and other gonadal neoplasms accounted for about 7% of all cancers occurring among Massachusetts children and adolescents less than 20 years old. During this time period, 175 germ cell, trophoblastic and other gonadal neoplasms were diagnosed among children and adolescents in the state (90 in males and 85 in females). The age-adjusted incidence rate of germ cell, trophoblastic and other gonadal neoplasms among Massachusetts children and adolescents less than 20 years old was the same for males and females, 1.1 per 100,000, from 1990-1999. The incidence rate of childhood germ cell, trophoblastic and other gonadal neoplasms in Massachusetts was similar to the national incidence rate based on SEER data for males, females, and total (Table 10).

Table 10: Age-adjusted incidence rates\* of germ cell, trophoblastic and other gonadal neoplasms among children and adolescents less than 20 years old, Massachusetts and SEER areas, 1990-1999

|         | Massachusetts | SEER areas |
|---------|---------------|------------|
| Males   | 1.1           | 1.3        |
| Females | 1.1           | 1.1        |
| Total   | 1.1           | 1.2        |

<sup>\*</sup>per 100,000. Age-adjusted to the 2000 U.S. Standard Population

#### **Trends**

Except for a slight deviation in 1995, the age-adjusted incidence rate of germ cell, trophoblastic and other gonadal neoplasms among Massachusetts children and adolescents less than 20 years old was about 1 case per 100,000 from 1990 to 1999 (Figure 25). The estimated annual percent change (EAPC) for these childhood cancers was 1.6% per year from 1990 to 1999, a slight increasing trend. This trend, however, was not statistically significant.

Figure 25: Incidence trends of germ cell, trophoblastic and other gonadal neoplasms among children and adolescents less than 20 years old, Massachusetts, 1990-1999

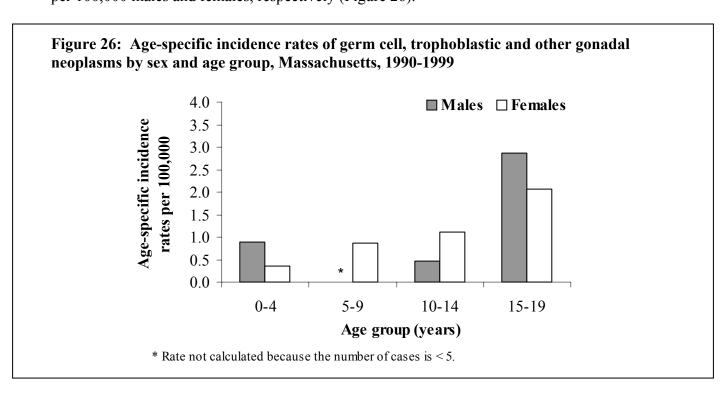
8.0
7.0
6.0
8.0
7.0
4.0
8.0
1.0
0.0
1990 1991 1992 1993 1994 1995 1996 1997 1998 1999

Year

\* Age-adjusted to the 2000 U.S. Standard Population.

#### **Age Patterns**

Between 1990 and 1999, Massachusetts adolescents 15-19 years old had the highest incidence rates of childhood germ cell, trophoblastic and other gonadal neoplasms, with 2.9 and 2.1 cases per 100,000 males and females, respectively (Figure 26).



### **Most Common Types**

Of all the germ cell, trophoblastic and other gonadal neoplasms occurring between 1990 and 1999 among Massachusetts children and adolescents less than 20 years old, 59% were gonadal germ cell tumors (Figure 27).

Figure 27: Distribution of germ cell, trophoblastic and other gonadal neoplasms among children and adolescents less than 20 years old by ICCC subgroup, Massachusetts, 1990-1999 Other and Other and unspecified unspecified malignant non-gonadal gonadal tumors germ cell 2.3% tumors 12.6% Gonadal carcinomas-10.3% Gonadal germ Intracranial and cell tumors intraspinal 59.4% germ cell tumors 15.4%

#### CARCINOMAS AND OTHER MALIGNANT EPITHELIAL NEOPLASMS

#### Overview

Carcinomas are many different cancers that develop from epithelial cells that form the lining of organs. Between 1990 and 1999, carcinomas and other malignant epithelial neoplasms were the third most commonly occurring cancers among Massachusetts females, accounting for about 15% of childhood cancer among females in the state. During this time period, only 74 cases of childhood carcinomas and other malignant epithelial neoplasms were diagnosed among males, compared to 183 cases diagnosed among females in the state. Between 1990 and 1999, the ageadjusted incidence rate of carcinomas and other malignant epithelial neoplasms among Massachusetts children and adolescents less than 20 years old was higher for females than for males, 0.9 per 100,000 for males and 2.4 per 100,000 for females. The incidence rate of childhood carcinomas and other malignant epithelial neoplasms in Massachusetts was similar to the national incidence rate based on SEER data for males and total, but was slightly higher than the national rate for females (Table 11).

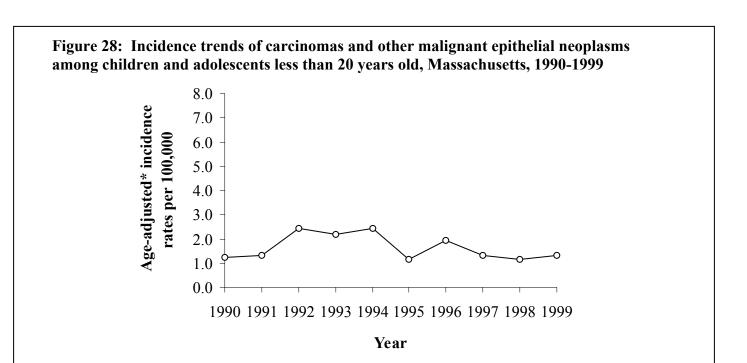
Table 11: Age-adjusted incidence rates\* of carcinomas and other malignant epithelial neoplasms among children and adolescents less than 20 years old, Massachusetts and SEER areas, 1990-1999

|         | Massachusetts | SEER areas |
|---------|---------------|------------|
| Males   | 0.9           | 1.0        |
| Females | 2.4           | 2.1        |
| Total   | 1.6           | 1.5        |

<sup>\*</sup>per 100,000. Age-adjusted to the 2000 U.S. Standard Population

#### **Trends**

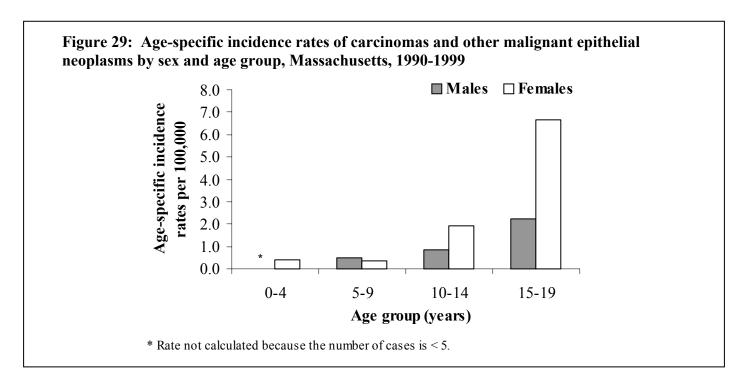
Between 1990 and 1999, the age-adjusted incidence rate of carcinomas and other malignant epithelial neoplasms among Massachusetts children and adolescents less than 20 years old fluctuated between 1.1 and 2.5 cases per 100,000 (Figure 28). The incidence rate of childhood carcinomas and other malignant epithelial neoplasms was 1.2 cases per 100,000 in 1990 and 1.3 cases per 100,000 in 1999. These childhood neoplasms showed a slightly decreasing trend and an estimated annual percent change (EAPC) of -2.6% per year from 1990 to 1999. Again, this trend was not statistically significant.



#### **Age Patterns**

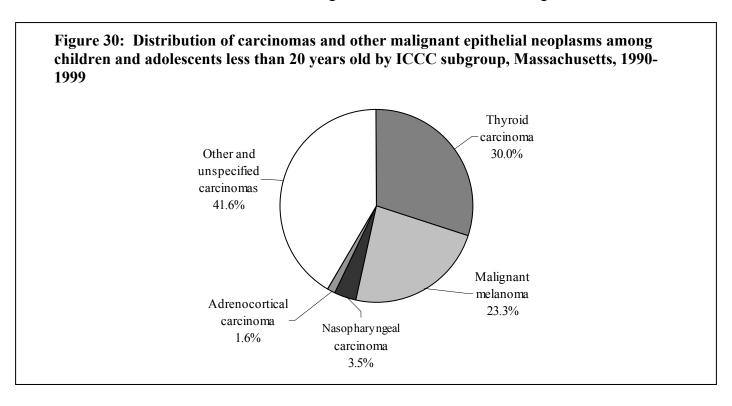
In Massachusetts between 1990 and 1999, females had a higher age-specific incidence rate of carcinomas and other malignant epithelial neoplasms than males for most age groups less than 20 years old. For both Massachusetts males and females less than 20 years old, the age-specific incidence rate of carcinomas and other malignant epithelial neoplasms was highest among those 15-19 years old. Massachusetts females in this age group had the highest incidence of childhood carcinomas and other malignant epithelial neoplasms from 1990 to 1999, with 6.7 cases per 100,000 (Figure 29).

\* Age-adjusted to the 2000 U.S. Standard Population.



#### **Most Common Types**

Of all the carcinomas and other malignant epithelial neoplasms occurring between 1990 and 1999 among Massachusetts children and adolescents less than 20 years old, 30% were thyroid carcinomas and 23% were melanomas (Figure 30). About 78% of the childhood thyroid carcinomas and 58% of the childhood malignant melanomas occurred among females.



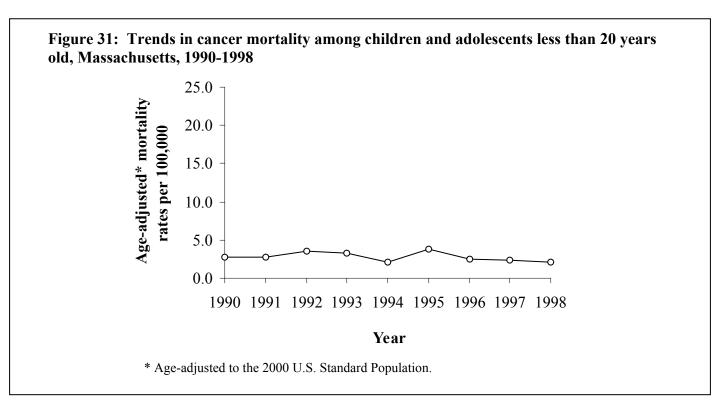
#### STATEWIDE PATTERNS OF CHILDHOOD CANCER MORTALITY

#### Overview

In Massachusetts in 1998, cancer was the second leading cause of death among children aged 1-14 years (9). During 1990-1998, 394 Massachusetts children and adolescents less than 20 years old died of cancer, approximately 40 deaths per year. About 61% of these childhood cancer deaths occurred in males and 39% in females. The average annual age-adjusted mortality rate of childhood cancer in Massachusetts during 1990-1998 was 2.8 deaths per 100,000. This mortality rate is slightly lower than the national mortality rate of childhood cancer during 1990-1998 of 3.1 per 100,000. In Massachusetts, the age-adjusted childhood cancer mortality rate was higher for males than females, 3.3 deaths per 100,000 males vs. 2.2 deaths per 100,000 females.

#### **Trends**

From 1990 to 1998, the age-adjusted mortality rate of childhood cancer decreased slightly for Massachusetts children and adolescents less than 20 years old (Figure 31). The age-adjusted mortality rate of childhood cancer was 2.7 deaths per 100,000 in 1990 and 2.1 deaths per 100,000 in 1998. During this time period, the estimated annual percent change (EAPC) for cancer mortality was -3.2% per year, reflecting a decreasing trend in childhood cancer mortality in Massachusetts from 1990 to 1998. This trend was not statistically significant. Similarly, mortality rates decreased nationally from 1975 to 1995 for all major cancer categories among children under age 15 years due to improvements in treatment and survival (7).

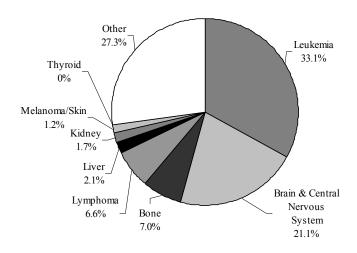


#### **Most Common Causes**

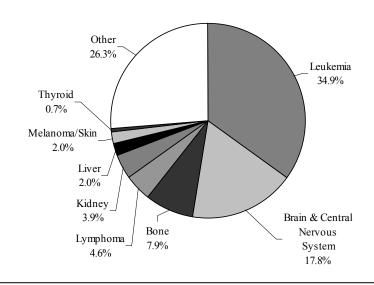
The four most common causes of cancer death among Massachusetts children and adolescents less than 20 years old from 1990 to 1998 were leukemias, followed by cancers of the brain & central nervous system and bone, and then lymphomas. During this time period, the ageadjusted mortality rate of each of these cancers overall was less than 1 per 100,000 (Appendix V). The top four causes of childhood cancer death in Massachusetts accounted for 68% of childhood cancer deaths in males and 65% of childhood cancer deaths in females. No other specific cancer site accounted for more than 4% of childhood cancer deaths in either sex (Figure 32).

Figure 32: Distribution of cancer mortality among children and adolescents less than 20 years old, Massachusetts, 1990-1998

#### **MALES**

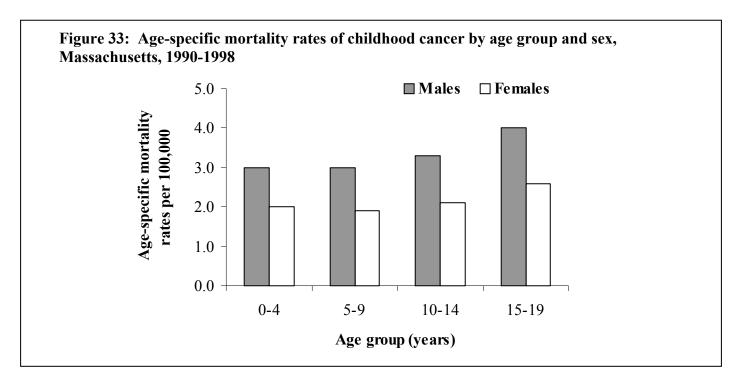


#### **FEMALES**



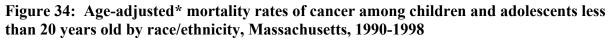
#### **Age Patterns**

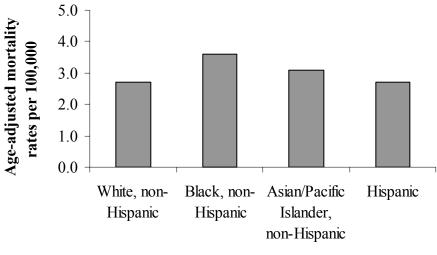
From 1990 to 1998, Massachusetts males had a higher age-specific mortality rate of childhood cancer than females for each age group. For both males and females, the highest mortality rates of childhood cancer were among those 15-19 years old (Figure 33).



#### **Race/Ethnicity Patterns**

Black, non-Hispanics had the highest overall age-adjusted cancer mortality rate among Massachusetts children and adolescents from 1990 to 1998, followed by Asian/Pacific Islander, non-Hispanics (Figure 34). During this time period, the age-adjusted mortality rate was 3.6 deaths per 100,000 for black, non-Hispanic children and adolescents and 3.1 deaths per 100,000 for Asian/Pacific Islander, non-Hispanic children and adolescents. White, non-Hispanic and Hispanic children and adolescents both had age-adjusted cancer mortality rates of 2.7 deaths per 100,000 from 1990 to 1998. However, it should be noted that many of the calculations in this report involve small numbers of cases. The differences in the rates may be due to chance, and the data should be interpreted with caution.





## Race/ethnicity

<sup>\*</sup> Age-adjusted to the 2000 U.S. Standard Population

## Appendix I International Classification of Childhood Cancer<sup>\*</sup>

|      |                                     | ICD-O-2** codes               |              |  |  |  |  |
|------|-------------------------------------|-------------------------------|--------------|--|--|--|--|
| ICC  | C Diagnostic Group                  | Morphology                    | Topography   |  |  |  |  |
| I.   | Leukemia                            |                               |              |  |  |  |  |
|      | a. Lymphoid leukemia                | 9820-9827, 9850               |              |  |  |  |  |
|      | b. Acute non-lymphocytic leukemia   | 9840, 9841, 9861, 9864, 9866, |              |  |  |  |  |
|      |                                     | 9867, 9891, 9894, 9910        |              |  |  |  |  |
|      | c. Chronic myeloid leukemia         | 9863, 9868                    |              |  |  |  |  |
|      | d. Other specified leukemias        | 9830, 9842, 9860, 9862, 9870- |              |  |  |  |  |
|      | -                                   | 9890, 9892, 9893, 9900, 9930- |              |  |  |  |  |
|      |                                     | 9941                          |              |  |  |  |  |
|      | e. Unspecified leukemias            | 9800-9804                     |              |  |  |  |  |
| II.  | Lymphomas and                       |                               |              |  |  |  |  |
|      | Reticuloendothelial Neoplasms       |                               |              |  |  |  |  |
|      | a. Hodgkin's disease                | 9650-9667                     |              |  |  |  |  |
|      | b. Non-Hodgkin's lymphoma           | 9591-9595, 9670-9686, 9690-   |              |  |  |  |  |
|      |                                     | 9714, 9723                    |              |  |  |  |  |
|      | c. Burkitt's lymphoma               | 9687                          |              |  |  |  |  |
|      | d. Miscellaneous lymphoreticular    | 9720, 9731-9764               |              |  |  |  |  |
|      | neoplasms                           |                               |              |  |  |  |  |
|      | e. Unspecified lymphomas            | 9590                          |              |  |  |  |  |
| III. | Central Nervous System and          |                               |              |  |  |  |  |
|      | Miscellaneous Intracranial and      |                               |              |  |  |  |  |
|      | Intraspinal Neoplasms               |                               |              |  |  |  |  |
|      | a. Ependymoma                       | 9383, 9390-9394               |              |  |  |  |  |
|      | b. Astrocytoma                      | 9380                          | C72.3        |  |  |  |  |
|      |                                     | 9381, 9400-9441               |              |  |  |  |  |
|      | c. Primitive neuroectodermal tumors | 9470-9473                     |              |  |  |  |  |
|      | d. Other gliomas                    | 9380                          | C70.0-C72.2, |  |  |  |  |
|      |                                     |                               | C72.4-C72.9  |  |  |  |  |
|      |                                     | 9382, 9384                    |              |  |  |  |  |
|      |                                     | 9442-9460, 9481               |              |  |  |  |  |
|      | e. Other specified intracranial and | 8270-8281, 8300, 9350-9362,   |              |  |  |  |  |
|      | intraspinal neoplasms               | 9480, 9505, 9530-9539         |              |  |  |  |  |
|      | f. Unspecified intracranial and     | 8000-8004                     | C70.0-C72.9, |  |  |  |  |
|      | intraspinal neoplasms               |                               | C75.1-C75.3  |  |  |  |  |

<sup>\*</sup> Chart from: Kramárová E, Stiller CA, Ferlay J, Parkin DM, Draper GJ, Michaelis J, Neglia J, Qureshi S (eds). *International Classification of Childhood Cancer 1996*. International Agency for Research on Cancer, International Association of Cancer Registries, International Society of Paediatric Oncology. IARC Technical Report No. 29. Lyon, France, 1996.

<sup>\*</sup> International Classification of Diseases for Oncology, 2nd Ed.

| IV.  | Sympathetic Nervous System<br>Tumors     |                               |              |
|------|--|-------------------------------|--------------|
|      | a. Neuroblastoma and                     | 9490, 9500                    |              |
|      | ganglioneuroblastoma                     | 7170, 7300                    |              |
|      | b. Other sympathetic nervous             | 8680, 8693-8710, 9501-9504,   |              |
|      | system tumors                            | 9520-9523                     |              |
| V.   | Retinoblastoma                           | 9510-9512                     |              |
| VI.  | Renal Tumors                             | 9610 9612                     |              |
| · 1• | a. Wilms' tumor, rhabdoid and clear      | 8960, 8964                    |              |
|      | cell sarcoma                             |                               |              |
|      | cen surconiu                             | 8963                          | C64.9, C80.9 |
|      | b. Renal carcinoma                       | 8010-8041, 8050-8075, 8082,   | C64.9        |
|      | o. Renar caremona                        | 8120-8122, 8130-8141, 8143,   | 001.5        |
|      |  | 8155, 8190-8201, 8210, 8211,  |              |
|      |  | 8221-8231, 8240, 8241, 8244-  |              |
|      |  | 8246, 8260-8263, 8290, 8310,  |              |
|      |  | 8320, 8323, 8401, 8430, 8440, |              |
|      |  | 8480-8490, 8504, 8510, 8550,  |              |
|      |  | 8560-8573                     |              |
|      |  | 8312                          |              |
|      | c. Unspecified malignant renal           | 8000-8004                     | C64.9        |
|      | tumors                                   | 0000 0001                     | 001.5        |
| VII. | Hepatic Tumors                           |                               |              |
|      | a. Hepatoblastoma                        | 8970                          |              |
|      | b. Hepatic carcinoma                     | 8010-8041, 8050-8075, 8082,   | C22.0, C22.1 |
|      |  | 8120-8122, 8140, 8141, 8143,  |              |
|      |  | 8155, 8910-8201, 8210, 8211,  |              |
|      |  | 8230, 8231, 8240, 8241, 8244- |              |
|      |  | 8246, 8260-8263, 8310, 8320,  |              |
|      |  | 8323, 8401, 8430, 8440, 8480- |              |
|      |  | 8490, 8504, 8510, 8550, 8560- |              |
|      |  | 8573                          |              |
|      |  | 8160-8180                     |              |
|      | c. Unspecified malignant hepatic tumors  | 8000-8004                     | C22.0, C22.1 |
| VIII | . Malignant Bone Tumors                  |                               |              |
|      | a. Osteosarcoma                          | 9180-9200                     |              |
|      | b. Chondrosarcoma                        | 9220-9230                     |              |
|      |  | 9231, 9240                    | C40.0-C41.9  |
|      | c. Ewing's sarcoma                       | 9260                          | C40.0-C41.9, |
|      |  |                               | C80.9        |
|      |  | 9363, 9364                    | C40.0-C41.9  |
|      | d. Other specified malignant bone tumors | 8812, 9250, 9261-9330, 9370   |              |

|             | a. Adrenocortical carcinoma                          | 8370-8375                     |                             |
|-------------|--|-------------------------------|-----------------------------|
| XI.         | Carcinomas and Other Malignant Epithelial Neoplasms  |                               |                             |
| <b>X7</b> ¥ |  | 8000-8004                     | C56.9,<br>C62.0-C62.9       |
|             | e. Other and unspecified malignant gonadal tumors    | 8590-8670, 9000               |                             |
|             |  | 8380, 8381, 8441-8473         |                             |
|             |  | 8510, 8550, 8560-8573         |                             |
|             |  | 8430, 8440, 8480-8490, 8504,  |                             |
|             |  | 8263, 8290, 8310, 8320, 8323, |                             |
|             |  | 8221-8241, 8244-8246, 8260-   |                             |
|             |  | 8155, 8190-8201, 8210, 8211,  |                             |
|             |  | 8120-8122, 8130-8141, 8143,   | C62.0-C62.9                 |
|             | d. Gonadal carcinomas                                | 8010-8041, 8050-8075, 8082,   | C56.9,                      |
|             | c. Commun gorin con tuniors                          | 7000 7102                     | C62.0-C62.9                 |
|             | c. Gonadal germ cell tumors                          | 9060-9102                     | C56.9,                      |
|             |  |                               | C73.9-C75.0,<br>C75.4-C80.9 |
|             |  |                               | C63.0-C69.9,                |
|             | gonadal germ cell tumors                             |                               | C57.0-C61.9,                |
|             | b. Other and unspecified non-                        | 9060-9102                     | C00.0-C55.9,                |
|             | cell tumors  | 20.60.0102                    | C75.1-C75.3                 |
|             | a. Intracranial and intraspinal germ                 | 9060-9102                     | C70.0-C72.9,                |
| <b>X.</b>   | Germ Cell, Trophoblastic and Other Gonadal Neoplasms |                               |                             |
|             |  |                               | C44.0-C80.9                 |
|             | e. Unspecified soft-tissue sarcomas                  | 8800-8804                     | C00.0-C39.9,                |
|             |  |                               | C47.0-C76.8                 |
|             |  | 9260                          | C00.0-C39.9,                |
|             |  |                               | C47.0-C80.9                 |
|             |  | 9231, 9240, 9363, 9364        | C00.0-C39.9,                |
|             |  |                               | C65.9-C76.8                 |
|             |  | 8963                          | C00.0-C63.9,                |
|             | Sarvoinas  | 9251, 9581                    |                             |
|             | sarcomas   | 9044, 9120-9134, 9150-9170,   |                             |
|             | d. Other specified soft-tissue                       | 8840-8896, 8982, 8990, 9040-  |                             |
|             | and other fibromatous neoplasms  c. Kaposi's sarcoma | 9561<br>9140                  |                             |
|             | b. Fibrosarcoma, neurofibrosarcoma                   | 8810, 8811, 8813-8833, 9540-  |                             |
|             | embroyonal sarcoma                                   | 0010 0011 0012 0022 0710      |                             |
|             | a. Rhabdomyosarcoma and                              | 8900-8920, 8991               |                             |
| IX.         | Soft-Tissue Sarcomas                                 |                               |                             |
|             | tumors   | 8804                          |                             |
|             | e. Unspecified malignant bone                        | 8000-8004, 8800, 8801, 8803,  | C40.0-C41.9                 |

| b. Thyroid carcinoma  c. Nasopharyngeal carcinoma | 8010-8041, 8050-8075, 8082,<br>8120-8122, 8130-8141, 8155,<br>8190, 8200, 8201, 8211, 8230,<br>8231, 8244-8246, 8260-8263,<br>8290, 8310, 8320, 8323, 8430,<br>8440, 8480, 8481, 8500-8573<br>8330-8350<br>8010-8041, 8050-8075, 8082,<br>8120-8122, 8130-8141, 8155,<br>8190, 8200, 8201, 8211, 8230,<br>8231, 8244-8246, 8260-8263,<br>8290, 8310, 8320, 8323, 8430,<br>8440, 8480, 8481, 8504, 8510, | C73.9        |
|---|---|--------------|
|   | 8550, 8560-8573   |              |
| d. Malignant melanoma                             | 8720-8780   |              |
| e. Skin carcinoma                                 | 8010-8041, 8050-8075, 8082,<br>8090-8110, 8140, 8143, 8147,<br>8190, 8200, 8240, 8246, 8247,<br>8260, 8310, 8320, 8323, 8390-<br>8420, 8430, 8480, 8542, 8560,<br>8570-8573, 8940   | C44.0-C44.9  |
| f. Other and unspecified carcinomas               | 8010-8082, 8120-8155, 8190-   | C00.0-C10.9, |
| 1   | 8263, 8290, 8310, 8314-8323,  | C12.9-C21.8, |
|   | 8430-8440, 8480-8580, 8940,   | C23.9-C39.9, |
|   | 8941  | C48.0-C48.8, |
|   |   | C50.0-C55.9, |
|   |   | C57.0-C61.9, |
|   |   | C63.0-C63.9, |
|   |   | C65.9-C72.9, |
|   |   | C75.0-C80.9  |
| XII. Other and Unspecified Malignant              |   |              |
| Neoplasms   |   |              |
| a. Other specified malignant tumors               | 8930, 8933, 8950, 8951, 8971-<br>8981, 9020, 9050-9053, 9110,<br>9580   |              |
| b. Other unspecified malignant                    | 8000-8004   | C00.0-C21.8, |
| tumors  |   | C23.9-C39.9, |
|   |   | C42.0-C55.9, |
|   |   | C57.0-C61.9, |
|   |   | C63.0-C63.9, |
|   |   | C65.9-C69.9, |
|   |   | C73.9-C75.0, |
|   |   | C75.4-C80.9  |

## Appendix II ICD-9 Codes\*

| Cancer site/type               | ICD-9 code                            |
|--------------------------------|---------------------------------------|
| Bone                           | 170                                   |
| Brain & Central Nervous System | 191-192                               |
| Kidney                         | 189.0-189.1                           |
| Leukemia                       | 204-208                               |
| Liver                          | 155                                   |
| Lymphoma                       | 200, 201, 202.0-202.2,<br>202.8-202.9 |
| Melanoma/Skin                  | 172-173                               |
| Thyroid                        | 193                                   |

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 $<sup>^* \</sup> International \ Classification \ of \ Diseases, \ Ninth \ Revision, \ Clinical \ Modification$ 

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# Appendix III CHILDHOOD¹ CANCER INCIDENCE BY SEX Massachusetts, 1990-1999

|  |               | Males          |        |               | Females        |        |               | Total          |        |
|--|---------------|----------------|--------|---------------|----------------|--------|---------------|----------------|--------|
| ICCC Diagnostic Group <sup>2</sup>   | <u>Number</u> | <u>Percent</u> | Rate 3 | <u>Number</u> | <u>Percent</u> | Rate 3 | <u>Number</u> | <u>Percent</u> | Rate 3 |
| All Groups   | 1427          | 100.0          | 17.4   | 1261          | 100.0          | 16.1   | 2688          | 100.0          | 16.7   |
| Leukemia   | 339           | 23.8           | 4.1    | 282           | 22.4           | 3.5    | 621           | 23.1           | 3.8    |
| Lymphomas and Reticuloendothelial<br>Neoplams                                      | 266           | 18.6           | 3.3    | 175           | 13.9           | 2.3    | 441           | 16.4           | 2.8    |
| Central Nervous System and Miscellaneous<br>Intracranial and Intraspinal Neoplasms | 249           | 17.4           | 3.1    | 211           | 16.7           | 2.7    | 460           | 17.1           | 2.9    |
| Sympathetic Nervous System Tumors  | 93            | 6.5            | 1.1    | 81            | 6.4            | 1.0    | 174           | 6.5            | 1.0    |
| Retinoblastoma   | 29            | 2.0            | 0.3    | 20            | 1.6            | 0.2    | 49            | 1.8            | 0.3    |
| Renal Tumors   | 63            | 4.4            | 0.7    | 58            | 4.6            | 0.7    | 121           | 4.5            | 0.7    |
| Hepatic Tumors   | 23            | 1.6            | 0.3    | 17            | 1.3            | 0.2    | 40            | 1.5            | 0.2    |
| Malignant Bone Tumors  | 77            | 5.4            | 1.0    | 60            | 4.8            | 8.0    | 137           | 5.1            | 0.9    |
| Soft-Tissue Sarcomas   | 122           | 8.5            | 1.5    | 77            | 6.1            | 1.0    | 199           | 7.4            | 1.2    |
| Germ Cell, Trophoblastic and Other Gonadal<br>Neoplasms                            | 90            | 6.3            | 1.1    | 85            | 6.7            | 1.1    | 175           | 6.5            | 1.1    |
| Carcinomas and Other Malignant Epithelial Neoplasms                                | 74            | 5.2            | 0.9    | 183           | 14.5           | 2.4    | 257           | 9.6            | 1.6    |
| Other and Unspecified Malignant Neoplasms  | 2             | 0.1            | *      | 12            | 1.0            | 0.2    | 14            | 0.5            | 0.1    |

 $<sup>^{\</sup>rm 1}$  children and adolescents less than 20 years old

<sup>&</sup>lt;sup>2</sup> Kramarova E *et al.* (eds). *International Classification of Childhood Cancer 1996.* IARC, IACR, SIOP. IARC Technical Report No. 29. Lyon, France, 1996.

 $<sup>^{\</sup>rm 3}$  per 100,000; age-adjusted to the 2000 U.S. Standard Population

<sup>\*</sup> age-adjusted incidence rate not calculated when number of cases < 5

Appendix IV

AGE-SPECIFIC INCIDENCE RATES<sup>1</sup> OF CHILDHOOD CANCER BY SEX

Massachusetts, 1990-1999

|  | 0-4 years    |                |              | 5-9 years    |                |              | 10-14 years  |                |              | 15-19 years  |                |              |
|--|--------------|----------------|--------------|--------------|----------------|--------------|--------------|----------------|--------------|--------------|----------------|--------------|
| ICCC Diagnostic Group <sup>2</sup>   | <u>Males</u> | <u>Females</u> | <u>Total</u> |
| All Groups   | 23.1         | 20.1           | 21.6         | 13.0         | 10.1           | 11.6         | 12.7         | 14.0           | 13.3         | 21.1         | 20.2           | 20.7         |
| Leukemia   | 7.5          | 7.0            | 7.3          | 4.0          | 3.1            | 3.5          | 2.4          | 2.3            | 2.4          | 2.6          | 1.9            | 2.2          |
| Lymphomas and Reticuloendothelial<br>Neoplams                                      | 1.2          | 0.6            | 0.9          | 2.5          | 0.7            | 1.6          | 3.0          | 2.3            | 2.6          | 6.6          | 5.4            | 6.0          |
| Central Nervous System and Miscellaneous<br>Intracranial and Intraspinal Neoplasms | 3.8          | 3.4            | 3.6          | 3.5          | 2.8            | 3.2          | 3.0          | 3.2            | 3.1          | 2.0          | 1.5            | 1.7          |
| Sympathetic Nervous System Tumors  | 3.7          | 3.5            | 3.6          | 0.3          | 0.3            | 0.3          | *            | *              | 0.2          | *            | *              | 0.1          |
| Retinoblastoma   | 1.4          | 0.9            | 1.1          | *            | *              | *            | *            | *              | *            | *            | *              | *            |
| Renal Tumors   | 2.2          | 2.0            | 2.1          | 0.5          | 0.6            | 0.5          | *            | *              | *            | *            | 0.3            | 0.2          |
| Hepatic Tumors   | 0.7          | 0.6            | 0.6          | *            | *              | *            | *            | *              | *            | 0.2          | *              | 0.2          |
| Malignant Bone Tumors  | *            | *              | *            | *            | 0.5            | 0.3          | 1.4          | 1.7            | 1.5          | 2.2          | 1.0            | 1.6          |
| Soft-Tissue Sarcomas   | 1.5          | 1.2            | 1.4          | 1.2          | 0.7            | 1.0          | 1.2          | 1.1            | 1.2          | 2.1          | 0.9            | 1.5          |
| Germ Cell, Trophoblastic and Other Gonadal Neoplasms                               | 0.9          | 0.3            | 0.6          | *            | 0.9            | 0.5          | 0.5          | 1.1            | 0.8          | 2.9          | 2.1            | 2.5          |
| Carcinomas and Other Malignant Epithelial Neoplasms                                | *            | 0.4            | 0.3          | 0.5          | 0.4            | 0.4          | 0.8          | 1.9            | 1.4          | 2.2          | 6.7            | 4.4          |
| Other and Unspecified Malignant Neoplasms  | *            | *              | *            | *            | *              | *            | *            | *              | *            | *            | 0.3            | 0.1          |

<sup>&</sup>lt;sup>1</sup> per 100,000

<sup>&</sup>lt;sup>2</sup> Kramarova E *et al.* (eds). *International Classification of Childhood Cancer 1996.* IARC, IACR, SIOP. IARC Technical Report No. 29. Lyon, France, 1996.

<sup>\*</sup> age-specific incidence rate not calculated when number of cases < 5

## Appendix V CHILDHOOD¹ CANCER MORTALITY BY SEX

Massachusetts, 1990-1998

|                                |               | Males          |        |               | Females        |        |               | Total          |        |
|--------------------------------|---------------|----------------|--------|---------------|----------------|--------|---------------|----------------|--------|
| Cancer Site / Type             | <u>Number</u> | <u>Percent</u> | Rate 2 | <u>Number</u> | <u>Percent</u> | Rate 2 | <u>Number</u> | <u>Percent</u> | Rate 2 |
| All Sites                      | 242           | 100.0          | 3.3    | 152           | 100.0          | 2.2    | 394           | 100.0          | 2.8    |
| Bone                           | 17            | 7.0            | 0.2    | 12            | 7.9            | 0.2    | 29            | 7.4            | 0.2    |
| Brain & Central Nervous System | 51            | 21.1           | 0.7    | 27            | 17.8           | 0.4    | 78            | 19.8           | 0.5    |
| Kidney                         | 4             | 1.7            | *      | 6             | 3.9            | 0.1    | 10            | 2.5            | 0.1    |
| Leukemia                       | 80            | 33.1           | 1.1    | 53            | 34.9           | 0.8    | 133           | 33.8           | 0.9    |
| Liver                          | 5             | 2.1            | 0.1    | 3             | 2.0            | *      | 8             | 2.0            | 0.1    |
| Lymphoma                       | 16            | 6.6            | 0.2    | 7             | 4.6            | 0.1    | 23            | 5.8            | 0.2    |
| Melanoma/Skin                  | 3             | 1.2            | *      | 3             | 2.0            | *      | 6             | 1.5            | 0.0    |
| Thyroid                        | 0             | 0.0            | *      | 1             | 0.7            | *      | 1             | 0.3            | *      |
| Other Sites                    | 66            | 27.3           |        | 40            | 26.3           |        | 106           | 26.9           |        |

<sup>&</sup>lt;sup>1</sup> children and adolescents less than 20 years old

<sup>&</sup>lt;sup>2</sup> per 100,000; age-adjusted to the 2000 U.S. Standard Population

<sup>\*</sup> age-adjusted mortality rate not calculated when number of cases < 5